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The Stigmatizing Effect of Tuberculosis Disease

Stigma in Tuberculosis Disease

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Abstract
Aim: This study aimed to measure the level of stigmatization using tuberculosis-related stigma (TRS) scale in healthy individuals and in patients with tuberculosis (TB) and to evaluate the factors affecting stigmatization.
Material and Methods: This cross-sectional survey study included healthy individuals (aged 18-75 years) admitted to Community Health Centre and patients with TB (aged 18-75 years) admitted to Tuberculosis Control Dispensary in Karabuk City of Turkey between July 2021 and October 2021. A questionnaire consisting of two parts, in which the first part included questions about sociodemographic characteristics and the second part included questions of Tuberculosis-Related Stigma (TRS) scale for the assessment of level of stigmatization, was applied to both healthy individuals and patients with TB using a face-to-face survey technique.
Results: The study included 360 healthy individuals (mean age: 45.46±12.90 years, female 65.3%) and 120 patients with TB (mean age, 41.15±16.42 years, male 60.8%). The mean total TRS scale score in healthy individuals was 18.60±4.18; those aged 36-53 years, those who were employed, and those living in the village had significantly higher TRS scale scores ($p<0.05$ for all). The mean total TRS scale score in TB patients was 19.72±3.20; those aged 18-35 years, single patients, those employed, and those with high- income level had significantly higher TRS scale scores ($p<0.05$ for all).
Discussion: The current study revealed that the level of stigma was higher in patients with TB. Additionally, it was thought that preventing stigma in TB patients would positively affect the treatment process.

Keywords
Stigma, Tuberculosis, Survey

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Introduction

Tuberculosis (TB) is a worldwide public health crisis. According to the 2019 report of the World Health Organization (WHO), TB affects around ten million people globally each year and is one of the top ten causes of mortality (available at: https://www.who.int/publications/i/item). The incidence of TB is 0.044% in Asia, 0.025% in Africa, 0.0029% in the Americas, and 0.0025% in Europe [1]. According to the Tuberculosis Control Dispensary (TCD) 2019 report, the incidence of TB in Turkey was 15.3%; 60.9% of the patients had pulmonary TB, 57.7% were males, 33.3% were over 65 years old, and 7.8% were relapse cases (available at: https://hsgm.saglik.gov.tr/depo/birimler / tuberkuloz_db/raporlar).

The causative agent of TB is Mycobacterium tuberculosis which is usually transmitted through the air. Among people with TB infection, 5-15% are at risk of developing TB at some point in their lives [2]. The disease affects the lungs at a rate of 65-70% [3]. Some diseases such as acquired immunodeficiency syndrome (AIDS), diabetes mellitus, chronic renal failure, some types of cancers, drug and alcohol addiction, tobacco use, and silicosis can lead to TB by impairing the immune system [4].

Unintentional emotions, thoughts, and actions of healthy individuals in society against people diagnosed with infectious diseases, such as TB, aimed at reducing their social status and standing, are referred to as "stigmatizing" behaviors [5]. It is known that 27-80% of patients with TB worldwide are subject to stigmatization in their family, social and work environment. Psychological trauma caused by stigmatizing behaviors can lead individuals to quit their job, divorce, dropout of education, and suicide [6]. It has been noted that some patients with TB who have the fear of stigmatization conceal their disease, start their treatment late, or do not receive treatment at all, which all result in high mortality [7].

Concealing the disease due to fear of stigmatization makes it impossible to take social measures for preventing transmission, accelerates the spread of the disease, and causes an increase in TB incidence [8]. Thus, for reducing morbidity and mortality rates in TB and for preventing its transmission to healthy individuals, early diagnosis and starting timely treatment are critical [9]. It is of great importance to raise awareness of populations towards TB about modes of transmission, disease duration, precautions to be taken, treatment process, and the importance and necessity of regular use of medicines [10]. It is thought that studies on this topic would play an essential role in reducing transmission, providing positive treatment outcomes, and increasing motivation, hope, and quality of life for individuals with TB. Accordingly, the current study aimed to measure the level of TB-related stigmatization using the TB-related stigma (TRS) scale in healthy individuals and in patients with TB and to evaluate the factors affecting stigmatization.

Material and Methods

This cross-sectional survey study was conducted in Karabuk Province of Turkey between July 2021 and October 2021 on newly diagnosed TB patients (n=123, aged 18-75 years), who were admitted to the TCD, and on healthy individuals (n=367, aged 18-75 years), who were admitted to the Community Health Center (CHS). Resistant cases in which the infection did not become negative despite more than six months of therapy and those having relapses were excluded. The healthy group was formed from those having a family member diagnosed with TB and/or working in a health-related field. All participants were included in the study without being sampled. Ten participants (7 healthy participants and 3 patients with TB) who incorrectly completed the study questionnaire were excluded. The study was approved by the Ethics Committee of Non-Interventional Clinical Researches of Karabuk University (No: E-77192459-050.99-48904 Subject: 2021/608) and Karabuk Governorship Provincial Health Directorate (No: 98024045-604.01.02). All participants were informed about the study and their written informed consent was obtained.

A questionnaire consisting of two parts was applied to both healthy individuals and patients with TB using a face-to-face survey technique. In the first part of the questionnaire, all participants were asked seven general questions about sociodemographic characteristics. In the second part, healthy individuals were asked 11 questions forming factor 1, and TB patients were asked 12 questions forming factor 2 of the Tuberculosis-Related Stigma (TRS) scale.

Tuberculosis-Related Stigma (TRS) scale

The TRS scale was first developed by Van Rie et al. [11], and the validity and reliability analysis of the Turkish version of the scale was performed by Küçük Şapçıoğlu (Küçük Şapcıoğlu E. Validity and reliability study of the tuberculosis-related stigma scale in Turkish population [Thesis]. İzmir: Ege University Institute of Health Sciences; 2012). Both factors of the TRS scale are 4-point Likert type scales, and each statement in the scale is scored from 0 to 3 (for positive questions: 0 points for "strongly disagree", 1 point for "disagree", 2 points "agree", and 3 points for "strongly agree"). There are no reverse-scored questions on the scale. For both factor 1 and factor 2 of the TRS scale, higher scores indicate higher levels of stigma and/or stigmatization. The lowest and highest scores obtained from the TRS scale were 0 and 33, respectively, for factor 1 (healthy individuals) and 0 and 36 for factor 2 (patients with TB). Cronbach's alpha coefficients for factor 1 and factor 2 of the TRS scale were 0.88 and 0.82, respectively (Küçük Şapcıoğlu E. Validity and reliability study of the tuberculosis-related stigma scale in Turkish population [Thesis]. Izmir: Ege University Institute of Health Sciences; 2012).

Statistical Analysis

Data analyses were performed using the IBM SPSS Statistics for Macintosh, Version 25 (IBM Corp., Armonk, NY, USA). Descriptive statistics were expressed as frequency, percentage, mean, and standard deviation, minimum-maximum (min-max). The Kolmogorov-Smirnov test was used to test the normality of quantitative data. The Mann-Whitney U and Kruskal-Wallis tests were used to determine whether the dependent variables fit the normal distribution. Statistical significance was set at a p-value of <0.05 for all analysis methods.

Results

This cross-sectional, survey study included 360 healthy individuals (mean age, 45.46±12.90 years, female 65.3%) and 120 patients with TB (mean age, 41.15±16.42 years, male 60.8%). The distribution of healthy individuals and patients

Table 1. Distribution of healthy individuals and patients with tuberculosis according to their sociodemographic characteristics

Introductory Characteristics	Healthy individuals (n=360)		Individuals with tuberculosis (n=120)	
	n	%	n	%
Age				
18-35	81	22.5	48	40.0
36-53	176	48.9	35	29.2
54-86	103	28.6	37	30.8
Gender				
Female	235	65.3	47	39.2
Male	125	34.7	73	60.8
Marital status				
Married	270	75.0	55	45.8
Single	51	14.2	32	26.7
Divorced/Widow	39	10.8	33	27.5
Educational Status				
Illiterate	0	0.1	12	10
Primary School Graduate	12	3.3	28	23.3
Secondary School Graduate	25	6.9	31	25.8
High School Graduate	76	21.1	32	26.7
University Graduate	247	68.6	17	14.2
Occupation				
Unemployed	142	39.4	79	65.8
Employee	218	60.6	41	34.2
Income Level				
Low	32	8.8	65	54.2
Middle	248	68.9	51	42.5
High	80	22.2	4	3.3
Place of Residence				
Village	12	3.3	56	46.7
Town	95	264	43	35.8
Province	253	70.3	21	17.5
Total	360	100.0	120	100.0

with TB according to their sociodemographic characteristics is presented in Table 1.

The mean TRS scale score was 18.60±4.18 (min-max, 9.0-29.0) in healthy individuals. In these individuals, while sex, marital status, educational level, and income level did not have a significant effect on the level of stigmatization (p>0.05, Table 2), age, employment status, and place of residence had significant effects (p<0.05; Table 2).

In patients with TB, the mean TRS scale score was 19.72±3.20 (min-max, 14.0±27.0). In patients with TB, while age, marital status, employment status, and income level had a significant effect (p<0.05, Table 3), sex and educational status did not affect the level of stigmatization (p>0.05, Table 3).

Mean TRS scale scores of TB patients who experienced guilt (21.55±1.66), anxiety (22.00±1.26), fear (19.37±2.20), and sadness (19.03±2.35) were significantly higher than the mean score of those without these feelings (17.66±1.58, 18.34±2.15, 16.76±1.98, and 16.00±.00, respectively) (p<0.05, Table 3). However, no significant difference was determined between the mean scores of patients with and without the feeling of loneliness (19.02±2.60 and 18.26±1.55, respectively; p>0.05; Table 3).

Table 2. Tuberculosis-Related Stigma scale scores of the healthy individuals (n=360)

Introductory Characteristics	Healthy individuals (n=360) (18.60± 4.18)	
	Mean ±SD	p
Age		
18-35	18.79± 4.93	KW*=8.599 p=0.014
36-53	19.07 ± 4.10	
54-86	17.66 ± 4.40	
Gender		
Female	44,19±12,6	z**=-1.053 p=0.297
Male	47,84±13,1	
Marital status		
Married	18.51±4.17	KW*=1.312 p=0.519
Single	18.90±5.78	
Divorced/Widow	18.84±4.10	
Educational Status		
Primary School Graduate	19.50±2.15	KW*=4.341 p=0.114
Secondary School Graduate	19.36±6.12	
High School Graduate	18.11±5.05	
University Graduate	18.63±4.08	
Occupation		
Unemployed	17.53±4.71	KW*=20.312 p=0.002
Employee	19.30±4.07	
Income Level		
Low	19.62±4.64	KW*=3.494 p=0.174
Middle	18.32±4.44	
High	19.07±4.20	
Place of Residence		
Village	21.00 ±3.69	KW*=8.169 p=0.017
Town	19.48±5.00	
Province	18.16±4.13	

TRS: Stigma Related to Tuberculosis SD: Standard Deviation; KW*: Kruskal Wallis-H test; z**: Mann-Whitney U coefficient; p<0.05 was considered significant.

Discussion

In the current study, which evaluated the stigma levels of healthy individuals and patients with TB, the TRS scale score was found as 18.60±4.18 and 19.72±3.20 in healthy individuals and in patients with TB, respectively. Accordingly, the stigma level was determined as moderate in both groups.

In the study conducted in a university hospital by Bayraktar and Khorshtd (2017) the stigma level in healthy individuals was reported as low with a mean TRS scale score of 13.87±6.26 [12]. In the current study, the stigma level was lower due to the fact that healthy individuals included in the study might also have relatives diagnosed with TB. Wynne et al. (2014) studied 360 healthy individuals in Uganda and found that 47% of them had highly stigmatizing attitudes towards patients with TB [13]. Bati et al. (2013) studied 422 healthy individuals with TB in rural areas in Ethiopia and found that 59.2% of healthy individuals had high levels of stigma towards TB patients [14]. The higher level of stigma associated with infectious diseases in the countries with a low level of education, such as Uganda and Ethiopia, can be explained by the fact that stigma is more common in underdeveloped societies. Crispim et al. (2017) assessed the stigma of TB patients and found a scale score of 83.1±0.2 [15]. The reason for the differences in stigmatization scores in the literature is thought to be due to the fact that

Table 3. Tuberculosis-Related Stigma scale scores of the patients with tuberculosis (n=120)

Introductory Characteristics	Individuals with tuberculosis (n=120) (19.72 ± 3.20)	
	Mean ±SD	p
Age		
18-35	21.08 ± 3.15	KW*=13.803 p=0.001
36-53	18.88 ± 3.39	
54-86	18.75 ± 2.44	
Gender		
Female	19.23 ± 2.92	z**=-1.057 p=0.291
Male	20.04 ± 3.35	
Marital status		
Married	19.49 ± 2.63	KW*=56.502 p=0.000
Single	22.87 ± 2.18	
Divorced/Widow	17.06 ± 2.12	
Educational Status		
Primary School Graduate	17.66 ± 2.99	KW*=6.632 p=0.085
Secondary School Graduate	18.57 ± 2.09	
High School Graduate	20.03 ± 3.28	
University Graduate	20.25 ± 3.61	
Occupation		
Unemployed	18.74 ± 2.31	KW* =34.399 p=0.000
Employee	19.00 ± 2.58	
Income Level		
Low	19.24 ± 3.35	KW*=7.937 p=0.019
Middle	20.07 ± 2.95	
High	23.00 ± .000	
Place of Residence		
Village	19.14 ± 3.32	KW*=9.251 p=0.010
Town	19.83 ± 3.41	
Province	21.04 ± 1.85	
Feelings About Their Illness Guilt		
No	17.66 ± 1.58	z**=-7.654 p=0.000
Yes	21.55 ± 1.66	
Anxiety		.
No	18.34 ± 2.15	z**=-5.299 p=0.000
Yes	22.00 ± 1.26	
Fear		.
No	16.76 ± 1.98	z**=-4.720 p=0.000
Yes	19.37 ± 2.20	
Loneliness		.
No	18.26 ± 1.55	z**=-1.676 p=0.094
Yes	19.02 ± 2.60	
Sadness		.
No	16.00 ± .000	z**=-3.823 p=0.000
Yes	19.03 ± 2.35	

TRS: Stigma Related to Tuberculosis; SD: Standard Deviation; KW*: Kruskal Wallis-H test; z**: Mann-Whitney U coefficient; p<0.05 was considered significant.

different scales are used in the studies and the studies are carried out in different geographical regions and cultural environments.

Bayraktar and Khorshtd (2017) measured the level of stigma in TB patients and found that the mean TRS scale score was 11.08±5.50 [12]. In our study, the stigma score in TB patients was found to be moderate (19.72±3.20), and TB patients were observed to feel more stigmatized. Öztürk (2018) used the Stigma Scale in Patients with Tuberculosis (SSPT) and found a mean score of 69.6±12.6 [5]. In our study, when examining patients with TB, the mean TRS scale score was 19.72±3.20 (min-max, 14.0±27.0). Açıkel and Pakyüz (2015) found that the stigma score of the patients with pulmonary TB was above average (83.79±7.42) in 74.4% of the patients [16]. Baltacı et al. (2021) used SSPT and determined the stigma score of 53.6% of TB patients to be above average (71.86±10.13) [17]. The SSPT developed by Sert (2010) (Sert H. Determination of stigma levels and affecting factors in patients with tuberculosis [Doctoral Thesis]. Istanbul Marmara University Institute of Health Sciences; 2010) was used in the studies by Öztürk [5], Açıkel and Pakyüz [16] and Baltacı [17]. In all three studies, more than half of the participants with TB reported that they experienced high levels of stigma due to TB. The higher stigma scores found in these studies compared to our results could have resulted from the difference in socio-demographic characteristics such as residence place, educational level, employment status, and gender of the participants. Crispim et al. (2017) used the Brazilian version of the TRS scale and reported the stigma score of TB patients as 62.7±0.2 [15]. Both healthy and TB individuals participated in this research, and it was found that the stigma level of the ill individuals was higher than that of the individuals with tuberculosis. On the other hand, in the present study, stigma scores were higher in individuals with TB likely due to ethnic differences.

Jittimanee et al. (2009) found that 65% of the human immunodeficiency virus (HIV)-infected TB patients experienced high levels of stigma in Thailand [18]. Stigmatization of AIDS patients ranks first and TB patients ranks second worldwide. It is thought that this situation arises from the lack of knowledge about infectious diseases in society; the factors such as ways of transmission, duration, and methods of protection against these diseases. We think that TB patients being co-infected with HIV significantly increase the rate of stigmatization.

In the current study, the evaluation performed on the emotional states of the TB patients revealed that 30% of the patients felt guilty, 13.3% felt anxious, 56.7% felt fearful, 93.3% felt sad, and 75% felt lonely. The mean TRS scale scores of TB patients who experienced guilt (21.55±1.66), anxiety (22.00±1.26), fear (19.37±2.20), and sadness (19.03±2.35) were significantly higher than the mean score of those without these feelings (17.66±1.58, 18.34±2.15, 16.76±1.98, and 16.00±.00, respectively). Bayraktar and Khorshtd (2017) found that among individuals with TB, 33.9% experienced guilt, 12.8% experienced anxiety, 14.7% experienced fear, 44% experienced sadness, 5.5% experienced pessimism, and 9.2% experienced anger [12]. Moreover, Ünalan et al. (2008) determined that 75.5% of their patients experienced acceptance, 43.4% experienced sadness, and 28.6% experienced fear, pessimism, anxiety, and anger [19]. In addition, Dhingra and Khan (2010) demonstrated that 60% of 1977 patients in India experienced anxiety, pessimism, restlessness, and anger [20].

According to Datiko et al. (2020), individuals stigmatized owing to TB had pessimistic feelings such as fear, anxiety, loneliness, and sadness in Ethiopia. Although the rates of emotions arising from stigma in TB patients differ from the results of the current study, they are similar in content. The difference in the percentage of feelings is thought to depend on factors such as education level, income level, place of residence, level

of knowledge about TB, isolation from the social environment, abandonment, or job loss [10].

In the current study, 60.8% of our patients were male. Similarly, in the study by Datiko et al. (2020) on stigmatization in TB in Ethiopia, the rate of male patients was 57.8% [10]. The average age of TB patients in the current study was 44.86±16.3 years, and 40% of the patients were aged between 18-35 years. In a study on stigmatization of TB patients by Baltacı et al. (2021), it was found that the mean age of patients was 46.96±14.21 years, and the age range was between 34-47 years [17]. The current study and other available studies indicate that TB is common in similar gender, mean age, and age range. Additionally, in the current study, 54.2% of TB patients reported their financial situation as "poor". In their study, Bayraktar and Khorshtd (2017) found that 69.7% of TB patients described their economic status as moderate [12]. The difference between the studies may be due to the differences in socioeconomic levels and self-report of income levels by the patients. In our study, the residential area where the TB disease was the most prevalent was urban (53.3%). Similarly, Mis and Karasungur (2016) also reported that 52.1% of their TB patients lived in the city center in Van Province [21]. These findings may be due to the fact that people living in the city centre do not register at health centers due to the fear of stigmatization, and thus they are late for treatment. The evaluation of the educational level of the TB patients in the current study revealed that the literacy rate was 90%. Similarly, Bayraktar and Khorshtd (2017) found the literacy rate to be 89.1% [12]. Based on the above-mentioned data, to the best of our knowledge, the findings of the socio-demographic characteristics of TB patients in other studies are mainly similar to the findings obtained in the current study.

The current study was conducted in a single center and TB patients did not want to participate in the survey due to fear of stigma, all of which can be considered limitations of the study. The lack of sufficient number of studies on the level of stigma in healthy individuals can be considered a strength of the study.

Conclusion

The present study demonstrated that the level of stigma towards TB individuals was higher in TB patients than in healthy individuals with both groups having moderate levels. The average TRS scale scores of individuals diagnosed with TB who experienced feelings of guilt, anxiety, fear, and sadness were significantly higher than those who did not experience these feelings. While age, employment status, and place of residence had significant effects on stigma level in healthy individuals, age, marital status, employment status, and income level had significant effects on stigma level in patients.

The adverse effects of stigmatization were identified in the current study and it was emphasized that individuals diagnosed with TB should be isolated from society as long as they are contagious and should follow treatment regularly. In addition, basic information was provided to end social isolation after eliminating the contagion, emphasizing both the individualistic and societal importance of the issue. TB patients experiencing guilt, fear, and sadness should receive psychological counseling from health care professionals. It is considered useful for instructors to favor active education methods such as role-playing from an early age so that healthy individuals can empathize with stigmatized TB patients.

Scientific Responsibility Statement

The authors declare that they are responsible for the article's scientific content including study design, data collection, analysis and interpretation, writing, some of the main line, or all of the preparation and scientific review of the contents and approval of the final version of the article.

Animal and human rights statement

All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. No animal or human studies were carried out by the authors for this article.

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Conflict of interest

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